

December 4, 2002

Dear Friend of IDF,

As the leading advocacy organization for individuals with primary immune deficiency diseases, the Immune Deficiency Foundation (IDF) would like to share with you both our position and concerns with the United States Government's impending plan to begin Smallpox vaccinations as a preemptive response to the threat of bioterrorism.

The threat of bioterrorism in the United States has been labeled a "clear and present danger" by government officials, and Smallpox tops the list of dangerous agents that might be used for these purposes. IDF supports the government's goal of providing safeguards in response to this threat—including the use of Smallpox vaccination strategies.

However, because the Smallpox vaccine is a **live virus vaccine**, it is possible that some individuals with primary immune deficiency diseases exposed to the virus—either through direct vaccination or through contact with a vaccinated individual—could suffer significant complications and in some cases death.

In short, both Smallpox itself and the Smallpox vaccine could pose major health risks to individuals with disorders of the immune system. These concerns are outlined in this letter and the enclosed Question and Answer sheet.

Specifically, IDF believes the following issues should be addressed immediately in the interest of providing adequate protection to primary immune deficient patients:

1. Implementation of a questionnaire at vaccination locations to identify undiagnosed primary immune deficient patients; and
2. Development and implementation of a clear public health message that both the vaccine AND recently vaccinated individuals pose risks to certain individuals by:
 - Communication of simple instructions to recently vaccinated individuals informing them of the potential for the virus to spread to others; and
 - Communication to the general public regarding these risks.

Currently, the U.S. Centers for Disease Control and Prevention (CDC) believe that individuals with specific types of primary immune deficiency diseases may be at higher risk of developing complications from the Smallpox vaccine. These diseases include cell-mediated immune deficiencies and antibody deficiencies. Examples of cell-mediated immune deficiency diseases include: Severe Combined Immunodeficiency (SCID), Wiskott-Aldrich syndrome, DiGeorge anomaly, Combined Immune Deficiency and Ataxia Telangiectasia. Examples of antibody deficiency diseases include: X-linked Agammaglobulinemia and Common Variable Immunodeficiency. However, because individuals with primary immune deficiency diseases vary in their responses to immunization and susceptibility to infection, IDF recommends **all** individuals with primary immune deficiency disease exercise caution when considering personal Smallpox vaccination or when in contact with a vaccinated individual.

We strongly encourage you to reference this letter as well as the enclosed materials in consulting with an Immunologist about the risks of the Smallpox vaccine to you or your family member. We hope that this will assist you in developing the best plan for you and your family. We will continue to communicate any new developments or information as they arise.

We invite you to call us at (800) 296-4433 if we can provide additional assistance.

Sincerely,

A handwritten signature in black ink, appearing to read 'T. Moran', with a long horizontal flourish extending to the right.

Thomas L. Moran
President

P. S. I would like to gratefully acknowledge Bayer Biological Products, makers of Gamimune® N 10%, for its generous support in helping to underwrite IDF's educational activities related to Smallpox, which is of such great importance to our community.